

2020-10-29

# 'I'm not an activist!': digital self-advocacy in online patient communities

Schermuly, AC

<http://hdl.handle.net/10026.1/16611>

---

10.1080/09581596.2020.1841116

Critical Public Health

Informa UK Limited

---

*All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.*

## **“I’m not an activist!”: digital self-advocacy in online patient communities**

### **Abstract**

For patient communities, digital media have dramatically transformed the options for action. This includes working collectively to change policies in ways that would have been difficult, if at all possible, before the internet. Yet, to date, the impacts of patients’ growing use of digital media on their sense of collective agency have been little explored. Drawing on the findings from an Australian study on patients’ use of digital media to access treatments (involving 50 interviews with participants from HIV/AIDS, breast cancer and neurodegenerative communities) and using a governmentality lens, this article sheds light on the changing character of patients’ sense of agency in an age of digital media. We identify a shift in patients’ conceptions of their agentic selves associated with the growing use of these media—from ‘activists’ to ‘advocates’—and consider the implications for critical public health. As we argue, this ‘digital self-advocacy’ is manifest in patients’ accounts of how they use digital media to achieve their goals and reflects the responsabilisation that is a hallmark of neoliberal governance. We suggest that digital self-advocacy offers a restricted vision of patient agency that limits rather than facilitates actions needed to respond to crises and to advance health justice. In our conclusion we consider whether the context and the nature of a condition or disease may also have a bearing on patients’ sense of agency in an age of digital media, making reference to patient responses to a new illness phenomenon dubbed ‘long COVID-19’.

**Key words:** digital media; patient activism; patient advocacy; governmentality; responsabilisation, long COVID-19

### **Introduction**

Studies that explore patient activists’ or advocates’ use of digital media are relatively few in number (Maslen & Lupton, 2019; Phillips & Rees, 2017; Rocha et al., 2018). The studies that have been undertaken show that digital media can provide novel opportunities for the agentic self, including co-producing and sharing knowledge and enacting chronic illness (e.g. Foster, 2016; Gonzalez-Polledo, 2016; Phillips & Rees, 2017). Indeed, proponents of digital media, which include many policymakers, clinicians and technology specialists, view these media as a means to empower individuals and communities through access to greater information and enhanced choice (see Lupton, 2013; Petersen, 2019). However, the use of the language of empowerment detracts from the profound implications of technologies on our lives, not all of which are positive. In particular, it

ignores the fact that digital media call upon users to conduct themselves in certain prescribed ways, in line with prevailing ideals of responsible citizenship.

This article examines the changing character of patient agency in an age of digital media. It explores the imperatives attached to the use of these media and how they shape the subjectivities of those who routinely use them to manage complex conditions. We draw on the findings from a study which aimed to characterise patients' use of digital media in Australia in three communities, HIV/AIDS, breast cancer and neurodegenerative conditions, respectively. Using a governmentality lens and making reference to the views of users from these communities, we explore the shift in patients' sense of collective agency associated with the use of these media—from 'activists' to 'advocates'—and consider the implications for critical public health. This 'digital self-advocacy', we argue, is manifest in patients' accounts of how they use digital media to achieve their goals and reflects the responsibilisation that is a hallmark of neoliberal governance. Digital self-advocacy is orientated not to challenging established power relations, and working for fundamental change, but rather to 'self-empowerment' through the use of technologies and working with partners (such as doctors and pharmaceutical companies) using one's own experiential knowledge. We highlight the limitations of digital self-advocacy for effecting long-term structural changes of the kind that scholars of critical public health identify as needed to improve people's lives. Finally, we consider whether the context and the nature of a condition or disease may also have a bearing on patients' sense of agency in a digital age, making reference to patient responses to a new illness phenomenon dubbed 'long COVID-19'.

We begin by situating our research in relation to the history of patient organisations and their use of digital media. We then explain the concept of governmentality that informs our analysis before describing the methods and presenting the findings.

### **History of patient organisations and their use of digital media**

Patient organisations have long been considered central to the apparatus of public health, specifically 'the new public health', which shares ideologies with new social movements such as discourses and practices of self-help, social and economic inclusion, empowerment and collaboration (Petersen & Lupton, 1996). Many social movements, in turn, have taken their cue from the identity-based civil rights (including Indigenous civil rights), gay rights and feminist movements of the 1960s. Therefore, patients mobilising to change aspects of healthcare has a shared foundation in identity-based politics.

Since the 1960s, the term 'activism' has been used to denote collective efforts to effect fundamental social change. The preferred method to achieve this has been *direct collective action*. This has generally been of a non-violent kind, including mass demonstrations and sit-ins which have served to publicly affirm collective identity and opposition to an identified 'oppressive' force, structure and/or ideology. Over time, there has been considerable fluctuation in the radicalism of political action with the old social movements based on workers' rights being replaced in the 1960s with movements such as those centring on women's rights or the peace movement and, since the 1980s, the rise of global justice movements (Della Porta & Diani, 2006). There is also a long history of patients creating alternative public spheres using traditional media to draw attention to their conditions (Gillett, 2003) and of activists co-opting media to serve their ends. This was most evident with early AIDS social movements but has also become a feature of health advocacy more generally (Mazanderani & Papparini, 2015). In the late 1960s, for example, activists within the women's liberation movement identified a gap in information about female bodies, health and sexuality, which led to the formation of the Boston Women's Health Book Collective (Our Bodies Ourselves, 2020). Inspired by developments in the United States (US), feminist activists in other countries established community health centres, maternal health services, and responses to breast cancer and other conditions solely or disproportionately affecting women and children (Nelson, 2015). In the 1970s and 1980s, movements increasingly organised around single diseases, comprising those living with a condition and survivors whose voices became identified as authoritative and persuasive (Tomes & Hoffman, 2011, p. 12). The best-known examples are the AIDS and breast cancer movements (e.g. Diedrich, 2016; Osuch et al., 2012). This is the context in which contemporary patient organisations have evolved.

The rise of the internet made collective action possible on an unprecedented scale. In the mid-1980s this involved small numbers of people who had access to computers (often based in the US) who used email and electronic bulletin boards. As a growing number of people in large urban centres in Western societies gained access to the internet in the early 1990s, online patient organisations flourished and gradually became more and more institutionalised (Gillett, 2003). One of the distinguishing features of contemporary movements is their focus on identity politics and a more individualised form of collective action (Castells, 2012). Furthermore, digital technologies including social media have facilitated stark changes in the way health and disease themselves are experienced, from previously being personal, private matters to being much more public and able to be shared in like-minded communities (Conrad et al., 2016). Therefore, the way one presents the

self as an ‘ill’ person (online) assumes greater significance, including the choice to identify as an activist or advocate. In their study of online patient groups, Griffiths et al. (2015) found that an individualistic approach can influence policy change. However, such change tends to be gradual, taking place within the confines of structures already in place (Griffiths et al., 2015). Furthermore, the forging of relationships online between like-minded individuals on health forums requires participants to present a version of themselves that exemplifies the way that they want to be perceived (Quinn & Papacharissi, 2017) which is where contestations over ‘activist’ and ‘advocate’ emerge.

### **Governmentality and responsabilisation**

Digital media tend to be viewed as neutral tools that facilitate empowerment. However, they operate as mechanisms of governance that profoundly shape views and conduct in many areas of contemporary life. The concept of governmentality, introduced by Foucault and developed by his adherents, explains how human agency is mobilised in ways that align human conduct and self-evaluations with broader political objectives (Bacchi, 2009; Dean, 2009; Rose, 1999). The term governmentality—or what Foucault originally called ‘governmental rationality’ (Gordon, 1991)—aims to distinguish between the different *mentalities* or regimes of government that seek to direct human conduct (Dean, 2009). A governmentality perspective is concerned overall with ‘how order is maintained’ (Bacchi, 2009, p. ix) and, in neoliberal societies, regimes that involve self-governance are favoured by governments. The result of this form of governing in the health domain is that the individual, as a responsible citizen, is assumed to be accountable for promoting and sustaining their own health so that the state’s role is diminished. The term used by Foucauldian scholars to capture this shift in personal accountability associated with neoliberalism is ‘responsibilisation’, which refers to the process whereby individuals are deemed responsible for matters for which the state was previously accountable or were not considered responsibilities at all (O’Malley, 2009).

Responsibilisation is reflected clearly in shifts in terms used to describe categories of conduct and agency such as ‘activism’ and ‘advocacy’. While both can be viewed as forms of agency that involve individuals taking responsibility for their own health, the former term conventionally refers to actions orientated to fundamental societal and ideological change typically working in opposition to established authorities and expertise. In contrast, the latter has developed less radical, more conservative connotations, implying the capacity to work *with* and *alongside* authorities and other established interests (e. g. government, pharmaceutical companies, medical professionals or government departments) to improve one’s own community’s health status. The pervasiveness of

responsibilisation, we suggest, is manifest in patients' practices and self-descriptions today, with individuals emphasising the importance of personal practices for responding to unmet healthcare needs. In addition, digital media are identified as a crucial tool for patients to undertake advocacy, with personal stories being a key means by which patients represent themselves as responsible, agentic individuals in line with the imperatives of self-governance and responsibilisation.

## **Methods**

Our study focuses on the digital media experiences of patients from three communities: HIV/AIDS, breast cancer and neurodegenerative conditions, which includes people who experience chronic pain. The first two communities have long, well-documented histories of activism corresponding with the rise of the internet; the third, while having a more recent history of patient participation, includes a range of conditions affecting many people. We employed surveys (n=302), comprising a combination of closed and open-ended questions, and qualitative interviews (n=50), which allowed us to explore issues in depth. In this article, we focus only on the findings from our interviews where respondents discussed the question of their identities as activists or advocates.

Recruitment was via patient activist and advocacy organisations (PAOs) who agreed to participate by displaying an advertisement that included a link to the survey on their websites, social media and/or newsletter. The recruitment wording used the term 'patient activists' which may have dissuaded some people who did not see themselves as 'activists' from participating. Nonetheless, we received responses from those who did and those who did not describe themselves as such. We acknowledge that those who participated may be somewhat atypical in being especially keen to use the opportunity provided by the interview to 'tell their story'. We are also aware that our method of recruitment may have excluded individuals who did not use electronic means at all in their correspondence with PAOs. However, it became evident early on in our research that to meaningfully engage with any of the organisations without being able to at least use email (and thus have access to an e-newsletter) would have been very difficult. Therefore, our recruitment method captured people with different degrees of engagement with digital media.

From the very start of the interviews, when participants were asked about how long they had been involved with patient activism, many individuals expressed doubt about the use of the term 'activist' to describe themselves. Consequently, this topic was reflexively incorporated into subsequent interviews. The largest group of interview participants (n=33) had neurodegenerative conditions,

including Parkinson's disease, episodic and spinocerebellar ataxias, epilepsy and a range of chronic pain conditions. Hence, we caution against generalising the findings to other patient communities.

The interviews were conducted face to face or over the telephone, were audio-recorded and transcribed and lasted 30 to 120 minutes. Interview topics included participants' reasons for getting involved in online patient forums, length of time involved and whether they thought their actions were effective in enacting change. Transcripts were read and analysed independently by each member of the research team, before thematic coding was carried out with the assistance of NVivo. A coding framework was devised using a grounded theory approach—based on prior themes identified through our literature review and coding of the transcripts. All interviewees were given pseudonyms to ensure privacy.

In analysing our findings, we used an interpretive approach, which aims for greater understanding of social phenomena via the perspectives of the people involved (Willis, 2007). Interpretivism foregrounds knowledge derived from the embodied experiences of participants, based on personal and individual realities in context. While we aimed to characterise patients' use of the internet and/or digital media in Australia to advance their health-related goals, we recognise that digital media are used by participants to construct identities that they wish to project to others online, as a 'good' patient, a survivor, a hero or an advocate or activist. We were particularly interested in the ways in which respondents sought to present themselves during the interviews, through their use of particular language and reference to certain views and practices. Notwithstanding the aforementioned qualifications regarding our sample, the study provides compelling insights into individual stories, practices and meaning making that contribute to what is known about patients' digital media use, online self-representations and mechanisms of governance.

## **Findings**

### *From activism to digital self-advocacy*

Our study focused on patients' use of digital media, and we did not set out to explore how respondents identified themselves. It was a surprising finding then that, during the interviews, certain individuals spontaneously expressed a clear preference for being referred to as 'advocates' rather than as 'activists', and this was often raised before any questions were asked. Only two participants asserted that they did not object to the use of 'activist' to identify themselves. One participant, Cam, from the HIV/AIDS online community, described himself as '...militant about the fact that [name of group] is a social change movement dressed up as a Facebook group...',

emphasising that militancy was a part of his online activism practices—something many other participants indicated that they deliberately avoided. HIV/AIDS communities have a long history of activism, often having had to vigorously resist the status quo (Gillett, 2003), and this culture appears to have endured as members have embraced digital media. The other participant, Lucy—a breast cancer survivor—commented: ‘I consider myself an activist in that I’ve ... lost friends because I just have to say something if somebody says something stupid [online].’ As with HIV/AIDS communities, breast cancer communities have a significant history of activism and Lucy was proud to speak out and espouse a more oppositional stance. However, many of the other participants from the breast cancer community preferred to be referred to as ‘advocates’, seeing their role as pedagogic; including raising awareness of issues and offering support informed by experiential knowledge. Likewise, respondents from communities comprising those with neurodegenerative conditions mostly preferred to be identified as ‘advocates’.

Many respondents believed that more could be achieved if they did not call themselves ‘activists’. Participants thought that a non-confrontational approach, aligning themselves *with* interests like the pharmaceutical industry, rather than being explicitly oppositional, would lead to better outcomes for their health. Chronic pain advocate, May, said: ‘Health activist? I’m not! I’m just a strong advocate’; Pete observed: ‘[Mine is]...more an advocacy role’ (Parkinson’s disease advocate). These comments were typical of respondents from neurodegenerative communities. Many of these participants appeared uncomfortable with the label of ‘activist’, although some acknowledged that it may apply to others. Chronic pain advocate, Dave, insisted: ‘I’m not an activist! ...I follow people who bring forward the activism ... I follow up on what they say, whether it relates to me and how it can help me’. Dave’s comments suggested he saw himself as playing a facilitative or mediating role rather than an initiating role, as did many of the other respondents.

What Dave described is a key feature of the emerging practice we term ‘digital self-advocacy’ because digital technologies make it possible for an individual to be a follower, mediator or facilitator. This practice, which involves different degrees of commitment, appeared to serve a crucial purpose. It allows an individual to simply gather information or to feel connected with others even if they are not feeling well. Being able to be a ‘lurker’ and/or agitator appears to be an integral feature of the success of online patient forums, enabling members to feel they are taking responsibility for aspects of their own health even if their condition precludes them from deeper involvement. That participants saw this as important is indicative of their commitment to taking responsibility for their own health. Being online demonstrated, even if in a small way, that they were responsible for themselves, despite being unwell.



Digital technologies provide ideal tools for enacting ideas of self-help and personal responsibility that constitute key components of self-governance. The *feeling* of empowerment that is fostered by the use of digital technologies, however, obscures the fact that no real power or agency to change one's circumstances necessarily accompanies that feeling (Petrakaki et al., 2018). Digital technologies invite a narrow focus on self-presentation, self-monitoring, responsabilisation, awareness raising and personal information gathering. Indeed, 'advocate' to our participants implied informed self-help; taking responsibility for one's own health rather than relying on others:

I don't see what I do as activism. I see it as ... an advocacy role... I give facts to lots of people and tell them ... about how it works and the basics to watch out for ... but ... I fill out the questionnaire too and say, "...[T]his has been bugging me. What do you guys do?" If I got onto the site and there was someone being ... an activist, I would probably leave and never return! (Pete, Parkinson's disease advocate)

Pete and others explained that activism to them meant agitating—trying to get others involved in actions outside of their comfort zone in order to enact change. On the other hand, advocacy was viewed as more relevant to contemporary systems and processes of governance. Several participants explained how their advocacy involved acting on their own behalf, using digital media to try and improve their health situation, which at the same time might (or might not) also benefit others.

For instance, among her other medical conditions, Gabriela was living with a rare translocation carcinoma of the kidney. Many doctors that she encountered during her frequent visits to the Emergency Department had no knowledge about her conditions, especially accounting for their multiple nature. This placed her in the role of 'expert patient' as well as self-advocate:

I don't think 'activism' is the right word. It would probably be 'advocate'... It can be really hard if you're a patient that has no representation in the community, even within the health industry or the health services available... (Gabriela, chronic pain advocate)

Gabriela was compelled to advocate for herself by finding information online about each condition she lived with so that she could be informed when she spoke to her doctors:

...if it wasn't for the internet, I would not have access to this...[For example], I get to contact the American Cancer Society. They have been very helpful in terms of trying to get articles for me and any little bit of news about this type of cancer.

Gabriela's situation demonstrated the way that participants felt they used digital media to empower themselves as 'digitally engaged patients' (Lupton, 2013, p. 256). In Gabriela's case, medical experts' apparent lack of knowledge about her conditions led to her feeling compelled to take the initiative in seeking information. The personal nature of these actions was one reason why participants like Gabriela did not view what they did as activism but rather self-advocacy, with the possibility that others may benefit being incidental. Significantly, there was a strong feeling among participants that, if they did not advocate for themselves, no-one would help them and they would be disadvantaged in terms of their treatment options through not having access to appropriate knowledge. In using digital media as she did, Gabriela was conducting herself in accordance with neoliberal imperatives that provide scope for the agentic self, but with options being largely predetermined (Leggett, 2014).

Moreover, maintaining an online connection with health forums was seen as the route to being able to attain privileges, such as finding out about joining a clinical trial, which could lead to accessing a treatment that would have otherwise been unavailable due to cost or approval status. Faye, who had a background as a senior nurse as well as being a breast cancer survivor and advocate, explained how engagement via online advocacy had given her the opportunity to try several experimental treatments that she may not have known about if she had not been as well connected:

I recently did something through the BCNA [Breast Cancer Network Australia] to do with... a new therapy that came online. I can't remember what it was, but it was a new tablet for stage IV breast cancer... also I'm part of a ... research project to do with looking at proteins and blood studies for a unique group of women that they've taken samples from.  
(Faye, breast cancer advocate)

Faye described how her use of digital media for advocacy had '...opened up [her] eyes in relation to other people who don't necessarily, have... all the same options that I had when I had my breast-cancer...'. Despite her considerable experience in nursing, her experience as a patient had given her a new perspective and heightened her awareness about the significance of alternative sources of information for patients and the role of patient narratives and real-world experience in the mix of information that patients sought. Online patient communities had, thus, evolved into repositories of information about different conditions and the means to share it:

I think there's lots of women out there who don't know where to go to get information... that don't necessarily have all the choices and get all the options or, at the time, they're so distraught that they don't ask all the right questions... I think social media has a place in giving people the option to go to sites, seek people up [sic], to ring someone at BCNA, and, get some straight answers; not always the print matter. But sometimes I think ... [breast cancer patients]...need to reach out to women who have lived experience.  
(Faye, breast cancer advocate)

Consistent with a healthcare system that mostly frames patients' experiences in individualised terms, Faye and other respondents presented themselves *as consumers* exercising choice in the market rather than as activists making claims on collective resources (see Tomes & Hoffman, 2011, pp. 18–19). As Faye's comments reveal, digital media are posited as tools for facilitating this choice, with personal stories ('lived experience') providing a means for empowering individuals in their negotiations with healthcare.

### *Digital self-advocacy as a governance mechanism*

Story-telling online was a way of enacting personal agency, feeling empowered by establishing oneself as a 'good' patient who takes responsibility for their own health. Presenting details of one's medical conditions online represents a form of confession, '...one of the West's most highly valued techniques for producing truth' (Foucault, 1990, p. 59). In Foucault's view, confessions are undertaken within a power relationship that necessitates the confessor being the subject in the presence of a more powerful agent, such as the state, that is able to reward or punish the confessor for their behaviour according to particular norms (Foucault, 1990). However, when patients confess online as storytellers, information providers or interpreters, they demonstrate to those with whom they connect that they are responsible for tasks that were previously undertaken by the state or other third parties.

Digital media also provided our respondents with the means to interpret or mediate the profusion of internet health information and personal illness narratives found online, while negotiating specialised support services, such as the National Disability Insurance Scheme (NDIS)<sup>1</sup>, or benefits offered by government agencies. In relation to accessing government assistance, participants emphasised that it was important to them to be seen to be making an effort to show that they are worthy of receiving financial help from the state. Mechanisms that encourage such behaviours are part of the concept of governmentality. Jill observed:

...in my last NDIS plan, the person that was doing the planning with me commented, "Do you do advocacy?" ... I thought, "Gee, I do, don't I?" It made me get thinking about the times that I respond to people and I have done a fair amount of giving information on how to access NDIS. When I initially did my... [application]... it took as much work as a university assignment to back up what I presented... for people who haven't done that level of work.., that must be very difficult.

---

<sup>1</sup> The National Disability Insurance Scheme (NDIS) is the way that the Australian Federal and State Governments fund services for Australians living with disabilities. More information can be found here: [https://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Library/pubs/rp/rp1617/Quick\\_Guides/DisabilityInsuranceScheme](https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/DisabilityInsuranceScheme)

(Jill, chronic pain and rare neurodegenerative conditions advocate)

Jill's experience indicated that a key purpose of being involved with online patient advocacy was to access information and take advantage of others' experiences in relation to information that proved invaluable when accessing government assistance. Accessing this information allowed her to navigate the complex process involved, thereby gaining a greater chance of success in receiving government benefits. Jill's experience involved demonstrating that she was 'worthy' of being granted government help. In cases like this, using digital media was viewed as offering a distinct advantage in a system where, if one was not able to self-advocate, one may not gain access to entitlements. Feeling compelled to demonstrate that one is exercising agency where possible and doing everything one can to help oneself is integral to showing one's self to be a responsible citizen.

The 'conduct of conduct' (Foucault, 1982, pp. 220–221) is performed when others respond to the sharing of personal illness experiences online with approval, suggestions or sanctions. The reactions from others in an online health forum to different ways of coping with chronic conditions sets the standard for what is considered to be a 'good' patient (and by implication a good citizen), thus, forum members will modify their behaviours accordingly. Dispensing 'validation' and 'advice' to others living with similar health challenges is a key feature of the way that digital self-advocacy operates as a governance mechanism. This is illustrated by Zoe's experience in the stroke survivor online community:

I started my own Facebook group ... it's general, for example, "I'm having a tough day." "Yes, it's okay to have tough days. We understand." It's kind of validation but also what has worked for other people. Advice.  
(Zoe, stroke advocate)

Zoe's advocacy as a younger person who had experienced a stroke was her own personal way of making sense of her experiences. She explained how the online groups she had initiated reflected her own journey to recovery and adjustment to her post-stroke identity and thus empowered her. Digital self-advocacy was therefore highly personal, a form of taking back control and exercising individual agency. Zoe also appeared to feel responsible for providing education, support and sources of information that she had not had during her own recovery. It is interesting that she thought this was *her* responsibility rather than that of the state or other parties such as medical experts and demonstrates the pervasiveness of neoliberal responsibilisation.

## Conclusion

In recent decades, digital media have been widely embraced by patient communities as valued tools for connecting with others and learning about and managing medical conditions. They offer options unavailable to patients until relatively recently, including working with authorities and credentialed experts to achieve their goals. However, our respondents' self-descriptions and accounts of their digital media use signify a shift in patients' sense of agency, responsibility and commitment from that envisaged and practiced in the early days of patient movements epitomised by HIV/AIDS and breast cancer activisms. That is, they see themselves more as consumers and mediators of information and advice than as troublemakers or agitators committed to overturning established relations of power. Their role, as our respondents portray it, is to source and share information, and exchange experiences—thereby tendering evidence of their adherence to the norms of responsible citizenship.

Digital self-advocacy, we suggest, offers a restricted vision of patient agency that ultimately limits rather than facilitates actions needed to advance health justice in its broadest sense. While digital media seem to offer patient communities the prospect of developing new forms of collective agency, harnessing the networking capabilities of these media to disrupt dominant power relations and develop more inclusive, 'bottom-up' ways of organising for change, they tend to be used in ways that are consistent with neoliberal responsibilisation. The forms of collective agency that originally underpinned patient communities aimed to address fundamental inequalities, discriminatory practices, physical environmental conditions and shortcomings in service provision that affect whole communities. This called for structural change and forms of collective response, such as the creation of women's health centres and of dedicated research programs (e.g. on HIV/AIDS) and policies to address inequalities based on differences of gender, ethnicity, class, age and sexual identity. Such forms of collective agency have not disappeared from patient communities; however, they are less evident than they once were, and this is reflected in our participants' accounts.

In light of this, it is important to consider whether patients' use of digital media is inherently individualising and responsibilising and hence limits the prospects for change, or whether this depends on the context and/or the nature of the disease or condition. At the time of writing, COVID-19 is highlighting the complexities of patient agency in a digitally mediated age. New forms of online collective action have emerged as lockdown measures have restricted social gatherings and physical protests against injustices. Patients who have been affected by the virus are using digital media in ways that reveal practices akin to the advocacy we have described *and* collective responses more in line with traditional activism. For example, the UK-based groups *#LongCovid* and *LongCovidSOS*

demonstrate this combined model of online patient action with ‘Rehab, Research, Recognition’ as their mantra (Long Covid, 2020; LongCovidSOS, 2020). Their sites demonstrate that, in addition to personal narratives, awareness raising and support functions (very similar to key elements of advocacy described by our respondents), gaining legitimacy for the condition and changing government policy towards those who are still suffering the effects of COVID-19 many months after the original illness are fundamental goals of these groups. Other organisations, such as US queer feminist forum Body Politic’s *COVID-19 Support Group*, explicitly refer to ‘medical advocacy’ (Body Politic, 2020) but appear to also combine functions similar to #LongCovid and LongCovidSOS; providing support and information and sharing experiences whilst also agitating to influence or even instigate policies relating to an emergent condition—in a manner similar to HIV/AIDS activism in the 1980s. It may be that, in the context of *new conditions with unknown longer-term impacts*, the focus and response of online patient organisations does manifest in a more emphatic and insistent (and ‘activist’) manner, whereas chronic conditions with familiar histories (such as those represented by the participants in our study) tend to adopt an ‘advocacy’ orientation over the longer term. More research is needed to determine whether the context and/or nature of a disease or condition influences the way that patients use the digital tools at their disposal and, hence, how they describe their actions, practices and identities. After all, as our research and recent examples of COVID-19 activism make clear, digital technologies are firmly established as indispensable tools for patient action. The critical question that needs asking is whether these tools are used to mobilise agency in ways that effect change in areas where it is urgently needed.

## Funding

This work was supported by the Australian Research Council under a Discovery Project, grant number DP170100402.

## References

- Bacchi, C. (2009). *Analysing policy: What’s the problem represented to be?* Frenchs Forest, NSW: Pearson Australia.
- Body Politic. (2020). COVID-19 Support Group. <https://www.wearebodypolitic.com/covid19>
- Castells, M. (2012). *Networks of outrage and hope: Social movements in the internet age (1<sup>st</sup> ed.)*. Cambridge, UK: Polity Press.
- Conrad, P., Bandini, J. & Vasquez, A. (2016). Illness and the internet: From private to public experience. *Health*, 20(1), 22–32.
- Dean, M. M. (2009). *Governmentality: Power and rule in modern society*. Los Angeles, CA: Sage Publications.

Della Porta, D. & Diani, M. (2006). *Social movements: An introduction* (2<sup>nd</sup> ed.). Oxford, UK: Blackwell Publishing.

Diedrich, L. (2016). *Indirect action: Schizophrenia, epilepsy, AIDS, and the course of health activism*. Minneapolis, MN: University of Minnesota Press.

Foster, D. (2016). 'Keep complaining til someone listens': Exchanges of tacit healthcare knowledge in online illness communities. *Social Science & Medicine*, 166, 25–32.

Foucault, M. (1982). The subject and power. In H. Dreyfus & P. Rabinow (Eds), *Michel Foucault: Beyond structuralism and hermeneutics* (pp. 208–226). Brighton, UK: Harvester Press.

Foucault, M. (1990). *The history of sexuality*. New York, NY: Vintage Books.

Gillett, J. (2003). Media activism and Internet use by people with HIV/AIDS. *Sociology of Health and Illness*, 25(6), 608–624.

Gonzalez-Polledo, E. (2016). Chronic media worlds: Social media and the problem of pain communication on Tumblr. *Social Media and Society*, 2(1), 1–11.

Gordon, C. (1991). Governmental rationality: An introduction. In G. Burchell, C. Gordon & P. Miller (Eds), *The Foucault effect: Studies in governmentality* (pp. 1–52). London, UK: Harvester Wheatsheaf.

Griffiths, F., Dobermann, T., Cave, J. A. K., Thorogood, M., Johnson, S., Salamatian, K., Gomez Olive, F. X., & Goudge, J. (2015). The impact of online social networks on health and health systems: A scoping review and case studies. *Policy & Internet*, 7(4), 473–496.

Leggett, W. (2014). The politics of behaviour change: Nudge, neoliberalism and the state. *Policy & Politics*, 42(1), 3–10.

Long Covid. (2020). About. <https://www.longcovid.org/about>

LongCovidSOS. (2020). Prime Minister Boris Johnson, respond to our SOS. <https://www.longcovidsos.org>

Lupton, D. (2013). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health*, 11(3), 256–270.

Maslen, S. & Lupton, D. (2019). Enacting chronic illness with and through digital media: A feminist new materialist approach. *Information, Communication & Society*, DOI: 10.1080/1369118X.2019.1602665

Mazanderani, F. & Paparini, S. (2015). The stories we tell: Qualitative research interviews, talking technologies and the 'normalisation' of life with HIV. *Social Science & Medicine*, 131, 66–73.

Nelson, J. (2015). *More than medicine: A history of the feminist women's health movement*. New York, NY: New York University Press.

O'Malley, P. (2009). Responsibilization. In A. Wakefield & J. Fleming (Eds), *The Sage Dictionary of Policing* (pp. 373–375). London, UK: Sage Publications.

Osuch, J. R., Silk, K., Price, C., Barlow, J., Miller, K., Hernick, A., & Fonfa, A. (2012). A historical perspective on breast cancer activism in the United States: From education and support to partnership in scientific research. *Journal of Women's Health*, 21(3), 355–362.

Our Bodies Ourselves. (2020). Our Story. <https://www.ourbodiesourselves.org/our-story/>

- Petersen, A. (2019). *Digital Health and Technological Promise: A Sociological Inquiry*. Abingdon, Oxon, UK: Routledge.
- Petersen, A. & Lupton, D. (1996). *The new public health: Health and self in the age of risk*. London, UK: Sage Publications.
- Petrakaki, D., Hilberg, E., & Waring, J. (2018). Between empowerment and self-discipline: Governing patients' conduct through technological self-care. *Social Science & Medicine*, 213, 146–153.
- Phillips, T. & Rees, T. (2017). (In)Visibility online: The benefits of online patient forums for people with a hidden illness: The case of multiple chemical sensitivity (MCS). *Medical Anthropology Quarterly*, 32(2), 214–232.
- Quinn, K. & Papacharissi, Z. (2017). Our networked selves: Personal connection and relational maintenance in social media use. In J. E. Burgess, A. E. Marwick & T. Poell (Eds), *The Sage handbook of social media* (pp. 353–371). London, UK: Sage Publications.
- Rocha, H.M., Savatt, J.M., Riggs, E.R., Wagner, J.K., Faucett, W.A., & Martin, C.L. (2018). Incorporating social media into your support tool box: Points to consider from genetics-based communities. *Journal of Genetic Counselling*, 27(2), 470–480.
- Rose, N. (1999). *Powers of freedom: Reframing political thought*. Cambridge, UK: Cambridge University Press.
- Tomes, N. & Hoffman, B. (2011). Introduction: patients as policy actors. In B. Hoffman, N. Tomes, R. Grob & M. Schlesinger (Eds), *Patients as Policy Actors* (pp. 1–16). New Brunswick, NJ: Rutgers University Press.
- Willis, J. (2007). *Foundations of Qualitative Research: Interpretive and Critical Approaches*. Retrieved from <http://srmo.sagepub.com.ezproxy.lib.monash.edu.au/view/foundations-of-qualitative-research/SAGE.xml>